Implementing GIPA:

How USAID Missions and their Implementing Partners in Five Asian Countries Are Fostering Greater Involvement of People Living with HIV/AIDS

Pablo Magaz
Karen Hardee

POLICY

January 2004

Implementing GIPA:

How USAID Missions and their Implementing Partners in Five Asian Countries Are Fostering Greater Involvement of People Living with HIV/AIDS

Pablo Magaz
Karen Hardee

POLICY Project

January 2004

Contents

Acknowledgments

Executive Summary

On behalf of the Asia/Near East Bureau (ANE) of the U.S. Agency for International Development (USAID), the POLICY Project undertook an assessment of how the Greater Involvement of People Living with HIV/AIDS (GIPA) Principle is being implemented in the ANE region. Five USAID Missions and 12 implementing agencies (IAs) in the region participated in the assessment, which was undertaken in May and June 2003 in Cambodia, India, Nepal, Philippines, and Viet Nam. The purpose of the assessment was to ascertain how Missions, IAs, and NGOs are incorporating GIPA principles into their organizations and into the programmatic work they support and implement. A self-administered questionnaire was completed by 23 respondents from Missions, IAs, and NGOs.

The assessment found a high level of awareness of GIPA and a commitment by most organizations to foster and promote GIPA principles, within their organizations and in the work they carry out. Ninety-one percent of respondents from the three types of organizations believe that their organizations' planning, programs, and policymaking activities are or would be enhanced by GIPA.

Organizations in the five countries are undertaking a wide range of activities to promote GIPA. USAID Missions apply GIPA principles by supporting IAs to carry out activities aimed at increasing people living with HIV/AIDS (PLHAs) involvement but do not have any means for incorporating GIPA into their own program planning and policy. Over half (58%) of the IAs and NGOs have initiated activities whose primary focus is aimed at promoting or achieving GIPA principles. These activities include developing stronger internal policies for recruitment of HIV-positive staff and providing care for those staff—including providing antiretroviral (ARV) drug therapy, assisting in the development and strengthening of PLHA organizations, conducting programmatic research on barriers to involving PLHAs, and involving PLHAs in advocating for policy change. Most IAs and NGOs (84%) also report engaging in efforts to involve PLHAs in HIV/AIDS project activities that did not have a primary focus on promoting GIPA.

Organizations have undertaken a number of strategies to overcome barriers to GIPA, including improving capacity and skills development, conducting advocacy and policy dialogue to generate support for GIPA, expanding networks of PLHA organizations and fostering collaboration among these groups, focusing on recruitment strategies, addressing poor health, and fostering GIPA in project decision making. Respondents made suggestions for further reducing barriers to GIPA at the country level, which include reducing stigma and discrimination, increasing access to voluntary counseling and testing (VCT), improving health care and access to treatment, strengthening the capacity of individual PLHA as well as PLHA organizations, increasing knowledge about HIV/AIDS and strengthening understanding of the need for GIPA, encouraging PLHAs to be spokespersons for HIV/AIDS, and reviewing and revising laws and policies related to HIV/AIDS and PLHAs.

Thus far, most involvement of PLHAs has been at the lower levels of the six-level UNAIDS GIPA involvement pyramid, including being involved as beneficiaries of project activities, as contributors, as speakers, or as implementers. Few organizations involve PLHAs at higher levels of the organization such as having PLHAs as paid staff, managers, or as experts or decision makers.

The assessment yielded several recommendations for more fully and effectively implementing GIPA principles.

Increase awareness of the applicability of GIPA. Organizations that implement HIV/AIDS projects and activities should include activities to sensitize government leaders and program managers in addition to civil society leaders and the general population on the needs of PLHAs and the value of including them in policy development and programs to prevent the spread of HIV/AIDS and mitigate its impact. The commitment of policymakers and program managers, in addition to donors and implementing organizations, is crucial to the effective implementation of GIPA.

Translate GIPA principles into clear implementation guidelines. USAID, other donors, and organizations that implement HIV/AIDS activities should work together to develop operational guidelines on how to implement GIPA principles, including for IAs and NGOs implementing USAID-funded projects. Guidelines are needed for implementing GIPA at the organizational level and at the project activity level. The guidelines should be widely disseminated in the ANE region and beyond.

Develop means within USAID Missions to involve PLHAs in strategic planning. Missions should identify and establish a means for ensuring GIPA in their own internal work. GIPA within USAID Missions could include hiring openly HIV-positive staff, creating a planning or advisory committee to assist Mission staff to identify programmatic priorities, review strategic plans, or evaluate program activities.

Train managers and staff to facilitate increased application of GIPA into organizational and program activities. USAID Missions in the ANE region should facilitate the development and implementation of a comprehensive training program on GIPA for Mission, IA, and NGO managers and staff. The training curriculum could be based on and complement the guidance document recommended above, with PLHAs playing key roles serving as trainers and facilitators.

Increase PLHA involvement at higher levels of the UNAIDS involvement continuum. USAID Missions and the organizations they fund should be encouraged to foster involvement of trained and qualified PLHAs at all levels of the organization and in project activities. Technical assistance to assist in this effort, as needed, should be funded by USAID.

Reduce stigma and discrimination as significant barriers to GIPA. Missions, USAID/Washington, and IAs should continue to develop and implement innovative methods to reduce stigma and discrimination. Having trained and qualified PLHAs in

leadership positions within the various types of organizations could send a powerful message and be an important strategy for stigma reduction.

Increase representation of various groups of PLHAs, including women, in PLHA organizations. USAID should support the development of special initiatives to ensure that leaders and representatives of PLHA communities reflect and represent affected populations relative to the epidemiology of the epidemic. Positive women, who also suffer from gender-related inequities throughout the region, should be particularly supported to participate in PLHA groups, including in leadership positions.

Base training and capacity-building activities with PLHAs on needs assessments of PLHA skills, abilities, and interests. USAID should support a systematic assessment of capacity-building needs of PLHAs; development of a comprehensive multilevel training curriculum; and an ongoing, country-specific, and regional inventory of opportunities for PLHA involvement. PLHA networks could play a prominent role in carrying out these activities.

Sustain GIPA by focusing on providing health care, access to treatment, and other support for PLHAs. Missions, USAID/Washington, and IAs should identify and implement appropriate policies and means to provide increased access to treatments, including ARV, and other financial and nonfinancial incentives to encourage GIPA. USAID should consider adopting a policy allowing for the use of project funds to cover necessary PLHA costs associated with their involvement in HIV/AIDS project activities.

Address conflict and competition among PLHA groups. Factors that may lead to conflict and competition between PLHA groups should be further explored. Policies and strategies for addressing potential or actual conflict among PLHA groups should be developed and incorporated in all GIPA-focused activities funded by USAID.

I.   Introduction

> *"Recognizing the important contributions people living with HIV/AIDS can make in response to the epidemic and to creating a space at all levels—locally, nationally and globally—for their involvement and contributions."*[1]

Articulated in a declaration issued at the Paris AIDS Summit in December 1994, GIPA principles are now recognized as a fundamental cornerstone to effective responses to HIV/AIDS by the Joint United Nations Programme on AIDS (UNAIDS), USAID, and the Global Fund to Fight AIDS, Tuberculosis (TB) and Malaria (GFATM).[2] Consensus on the importance and validity of GIPA is reflected by its endorsement in numerous international statements, most recently, the *Declaration of Commitment on HIV/AIDS,* signed by the 189 member states of the United Nations in 2001.[3]

USAID identifies GIPA as one of the 10 crosscutting program components by which the agency implements its HIV/AIDS strategy. USAID "believes that the involvement of people living with HIV/AIDS in designing and implementing prevention and care activities is essential to these activities' sustained success. People living with HIV/AIDS have a critical role to play…"[4]

While there is broad consensus on the importance of GIPA as a principle, little programmatic experience and research is available to guide policymakers and other stakeholders, including PLHAs, in implementing GIPA.[5]   What is meant by GIPA? What activities can be considered GIPA-focused? Should organizations working on HIV/AIDS be required to incorporate GIPA into policy and decision-making bodies in addition to program delivery? What is "meaningful" participation? How can GIPA be measured and what are benchmarks of achievement?   Beyond these questions, issues pertaining to "meaningful" involvement of PLHAs at all levels of the policy and programmatic response are gaining increased urgency. At what levels of the decision-making processes are PLHAs involved? Are PLHAs serving as advisors, but have no decision-making power? Within the NGO sector, at what levels of are PLHAs involved? Are PLHAs only used as occasional volunteers and/or models for posters and

---

[1] Adapted from "From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)." UNAIDS Best Practice Collection. 1999.

[2] The 1983 Denver Principles, which evolved when a group of PLHA protested their exclusion in planning workshops related to AIDS at a gay and lesbian medical conference, also promoted involvement of people most directly affected by the pandemic.

[3] United Nations General Assembly Special Session on HIV/AIDS, 2001.

[4] USAID web site http://www.usaid.gov/pop_health/aids/TechAreas/people/index.html.

[5] Good resources on GIPA include the Population Council Horizons Project's 2002 research on PLHA participation titled *The Participation of PLHA in Community-Based Organizations,* and the UNAID's Best Practice Collection 1999 report titled *From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA).* The *Directory of Associations of People Living with HIV/AIDS,* published by USAID in 2002 and soon to be updated and reissued, is another useful tool for PLHAs looking to become more involved in their country's response to HIV/AIDS, and for donors, program managers, and policymakers committed to increasing GIPA efforts.

publications of HIV prevention communication campaigns? Do PLHAs have a face but no voice? Is there a danger that PLHA participation may become tokenistic and co-opted.

This report summarizes the findings of an assessment of GIPA undertaken by the POLICY Project on behalf of USAID's Asia/Near East Bureau. The assessment took place in May–June 2003 in Cambodia, India, Nepal, Philippines, and Viet Nam. Five USAID Missions and 13 IAs and NGOs in those countries participated in the assessment. The objective of the assessment was to ascertain how Missions and IAs are incorporating GIPA principles into their organizations and in the HIV/AIDS projects and activities they support and implement.

Although the sample size for this assessment is small, this "snapshot" of the current state of GIPA within USAID and its programs in the ANE region indicates strong support for GIPA and at the same time raises a number of important challenges regarding meaningful participation on PLHAs within the organizations and in the work carried out by USAID and the IAs and NGOs it funds. The findings will be useful to USAID, other donors, IAs, and stakeholders in identifying priority needs and programmatic directions for more complete implementation of GIPA in the region.

II.   Methodology

Five countries—Cambodia, India, Nepal, Philippines, and Viet Nam—were selected to participate in the study based on several factors, including HIV prevalence rates, strength of existing PLHA networks, and the number and size of USAID-funded IAs working on HIV/AIDS. Thirty-four programs, representing five USAID Missions, one regional ANE office of USAID, and 28 USAID-funded projects (implemented by 13 IAs and NGOs), were invited to participate in the study.

The USAID ANE Bureau sent an introductory letter to the 34 programs advising them of the study and requesting their participation. One IA declined because it did not have HIV/AIDS programs. The self-administered questionnaire was subsequently distributed electronically to 33 programs. Twenty-three completed questionnaires were returned, for a response rate of 70 percent. The final sample of organizations included four Missions, Family Health International (four countries), Futures Group/POLICY Project (five countries), Population Services International (three countries), Population Council, University Research Corporation, Care, PATH, Avert, Khana, and a Reproductive Health Association. Those who responded to the assessment questionnaire were senior-level program managers and staff. The job tenure of the respondents ranged from two months to nine years.

The questionnaire elicited information on:

- The organization's HIV program and GIPA within the organization and its program;
- Respondent's understanding, knowledge, and awareness of local and national GIPA activities of their organizations and other NGOs;
- Collaboration across organizations;
- Barriers and drawbacks to GIPA;
- Strategies for enhancing GIPA efforts;
- Priority needs to enhance GIPA; and
- GIPA achievements.

III.   Findings

A.   *USAID Missions in ANE support a wide range of HIV/AIDS-related programs for a number of target groups*

USAID Missions, in coordination with their regional bureau, the Bureau for Global Health, and the Bureau for Policy and Program Coordination, have primary responsibility for establishing and achieving strategic objectives related to HIV/AIDS in their respective countries. To achieve strategic objectives, Mission staff carry out "program development, problem analysis, project design, program/budget documentation, implementation monitoring, financial management, and administrative/logistical support activities."[6] Missions do not directly implement programs. Instead, through contractual arrangements, they develop partnerships and collaborations with private voluntary organizations, indigenous organizations, universities, American businesses, international agencies, other governments, and other U.S. government agencies to implement projects and activities to meet their strategic objectives.

ANE Missions participating in this study have developed partnerships for HIV/AIDS services and activities with a number of international and local organizations, 10 of which are represented in this assessment. These 10 organizations currently manage 28 HIV/AIDS projects with budgets ranging from $150,000 to $6.8 million. The organizations worked at various levels in the countries, from projects focusing on certain local areas to others working nationally.

The 19 IA and NGO programs represented a wide range of activities on the continuum of prevention to care. Figure 1 shows that the most commonly reported activities included prevention, noted by 74 percent of IAs and NGOs, advocacy (58%), and voluntary counseling and testing (VCT), condom distribution, and research (47% each). Forty-two percent were involved in policy activities and 37 percent in treatment and care. Four organizations (21%) reported including prevention of mother-to-child transmission (PMTCT) in their country programs.

---

[6] "ADS 101–Agency Programs and Functions," USAID Website:
http://www.usaid.gov/policy/ads/100/101.pdf.

Figure 1. HIV/AIDS Activities of Selected USAID-funded IAs and NGOs in Five Asian Countries: 2003
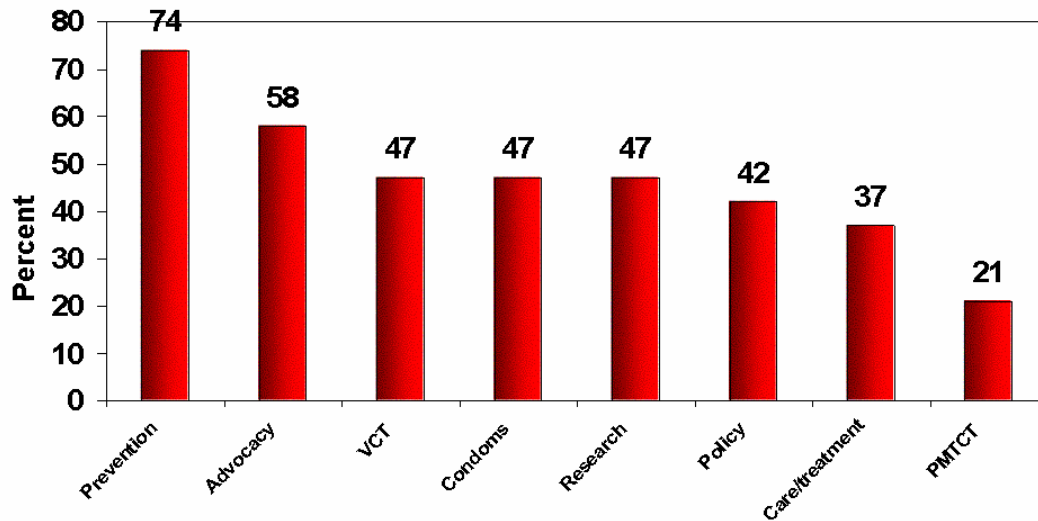
The IAs and NGOs reported targeting a range of groups in the programs their organizations support (Figure 2). The largest percentage of organizations (79%) targeted prostitutes. Other groups likely to be included in programs were heterosexual men (74%), women and youth (63% each), the general population and PLHAs (58% each), homosexual and bisexual men (53% each), and policymakers. Fewer than half targeted injecting drug users (IDUs) and children (42% and 37%, respectively).

Figure 2. Target Groups Served Through USAID-funded HIV/AIDS Projects of Selected IAs and NGOs in Five Asian Countries: 2003
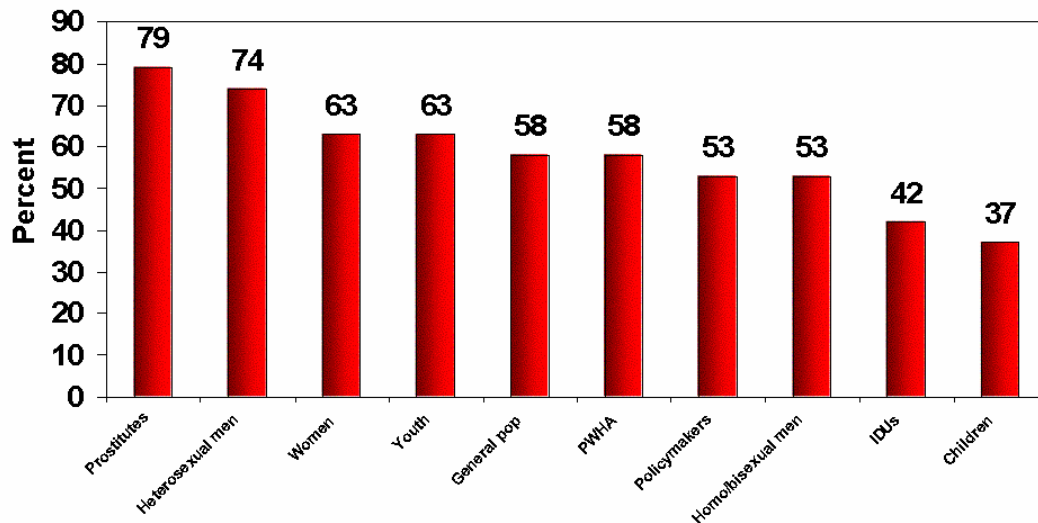
B. Knowledge and awareness of GIPA is high

Three of the four[7] USAID respondents and 95 percent of the IA and NGO respondents were familiar with the concept of GIPA and were able offer a definition of it. The depth of understanding varied from one IA respondent who said, *"[Our] understanding is very limited,"* to a USAID respondent who noted, *"It means recognizing that people infected or affected by HIV/AIDS can make important contributions toward addressing the HIV epidemic, and that there is a need to establish and define a place in all aspects of the HIV response (civil society, government,…) to include them."* Generally, the respondents had a good understanding of what GIPA means.

C. Application of GIPA mirrors the mandates of the IAs and NGOs

Three of the four USAID Mission respondents indicated that application of GIPA is a component of the programs their Missions support. The fourth USAID respondent said his/her Mission did not actively apply GIPA because HIV prevalence is low in the country and because it is focusing on HIV prevention.[8] Among the IAs and NGOs, 16 of the 19 (84%) indicated how GIPA is applicable to the work of their organization. One IA respondent noted, *"It is fundamental in that we are mandated to assist in the promotion and enhancement of GIPA."* Another IA respondent made a similar point, saying, *"GIPA*

---

[7] Although the fourth USAID respondent did not indicate an awareness of GIPA principles, the person noted a number of GIPA-related activities supported by the Mission.

[8] The respondent did note, however, that there is a role for PLHAs in prevention activities.

is one of the crosscutting themes of all programs undertaken by [this] country office."
An NGO respondent explained his/her organization's perspective on the applicability of
GIPA: *"In order to follow up clients who are HIV positive, we need strong networks and
good referral mechanisms. PLHAs and support groups play a very important role in
both counseling and home-based care."* Another IA respondent explained, *"We have
incorporated it into our recruitment policy."*

Over half (58%) of the IAs and NGOs have initiated activities whose primary focus is
aimed at promoting or achieving GIPA principles. A number of IAs and NGOs are
responding to GIPA within their organizations by developing stronger internal policies
for recruitment of HIV-positive staff and providing care for those staff, including
provision of antiretroviral drug therapy (ART). Externally, fostering GIPA has included
a number of activities, including assisting in the development and strengthening of PLHA
organizations, conducting programmatic research on barriers to involving PLHAs, and
involving PLHAs in advocating for policy change. IA and NGO activities to promote
GIPA are listed in Box 1.

Box 1. IA and NGO Application of GIPA

"Affirmative action in employment of people with HIV on staff." IA

"Ensuring that high-risk groups in which the epidemic is currently concentrated are
represented in program design, implementation, and evaluation both at the country
office as well as among implementing partners." IA

"Provides both technical and financial support to [PLHA groups] for advocacy,
policymaking as well as capacity building." NGO

"Supporting the development of independent PLHA groups and working toward
assisting the creation of a national network of PLHA organizations." IA

"A PLHA national body is a full-time voting member of the board of the society, which
is the highest policy body." NGO

"Conducted a media review of reportage of HIV/AIDS. The results of the review will
be used to develop media advocacy tools kits for journalists." IA

"PLHA are members of in-country ethical and advisory committees who are involved
in guiding the design of the research as well as in review and approval of the activity."
IA

"Funding a model community-based comprehensive prevention to care project…This
project is being implemented by [a group of PLHA organizations]." IA

Most IAs and NGOs (84%) also report engaging in efforts to involve PLHAs in HIV/AIDS project activities that are not specifically designed to promote GIPA (Figure 3). The most common means of involvement in the non-GIPA-specific activities is to include PLHAs as speakers at training or other events, noted by 74 percent of the respondents. Additionally, 37 percent of the respondents noted that their organizations foster GIPA in these activities through using PLHAs as volunteers and staff. Nearly one-third (32%) of organizations use PLHAs as spokespersons, including in social marketing campaigns. Three (16%) of the organizations use PLHAs in management positions to foster GIPA in non-GIPA-specific activities.

Figure 3. Efforts to Involve PLWHA in Non-GIPA-specific Project Activities of Selected USAID-funded IAs and NGOs in Five Asian Countries: 2003
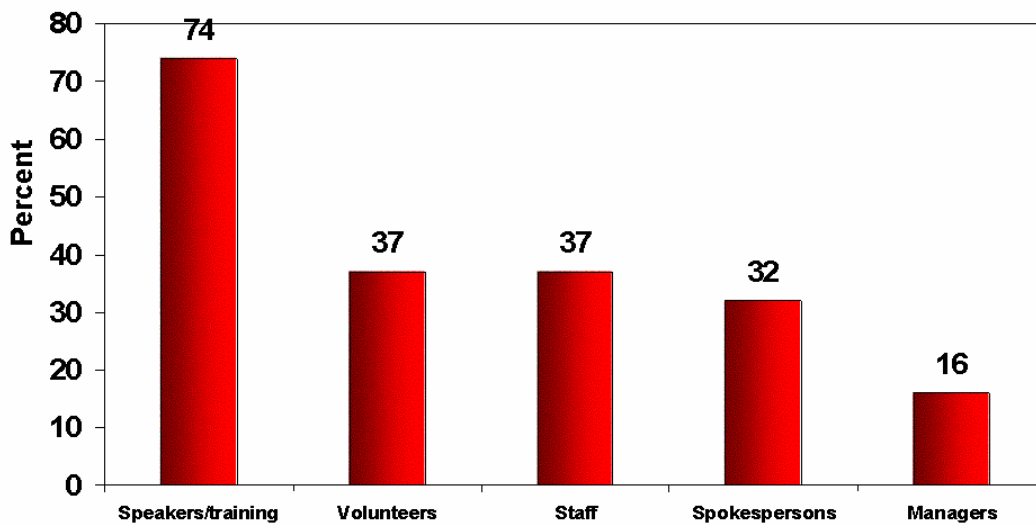
D.   GIPA tends to be at lower levels of the involvement

Using the UNAIDS framework to categorize PLHA involvement along six increasing levels, starting as the target audience (beneficiaries), and moving up as contributors, speakers, implementers, experts and finally as decision-makers (see Appendix), it is clear that PLHA involvement in IA and NGO programs primarily falls within the lowest four levels. PLHAs tend to be involved as beneficiaries of project activities, as contributors, as speakers, or as implementers. Few IAs and NGOs presently involve PLHAs as experts or as decision makers.

8

E.   IAs and NGOs are aware of other GIPA-related activities in their countries

Seventy percent of USAID Missions, IAs, and NGOs report that they are aware of and collaborate with other organizations in the country that conduct GIPA-related activities (Box 2).

Box 2. Collaboration with Other Organizations in GIPA-related Activities

- Several USAID Missions and IAs are members of their United Nations Development Program (UNDP) HIV/AIDS country programs.
- IAs are assisting local subgrantees to incorporate GIPA into their community and home-based service delivery programs.
- IAs in two countries are providing technical assistance to national governments to facilitate and increase participation of PLHA in the development of national AIDS plans and strategies.

F.   Missions, IAs, and NGOs face barriers to enhancing GIPA in their programs and projects

Missions, IAs, and NGOs noted a number of challenges their organizations have encountered in implementing GIPA-related activities (Figure 4). The main barrier, noted by 74 percent of USAID, CA, and NGO respondents combined, is that PLHAs lack the skills to participate in project activities. This finding is consistent with other studies.[9] Other barriers included lack of funds to adequately compensate PLHAs for their volunteer efforts or costs related to participation, which was mentioned by 35 percent of the respondents, and the poor health status of PLHAs, which 30 percent of respondents noted. Twenty-six percent each said that PLHAs are unwilling to participate in project activities, due in part to the fear of being stigmatized for doing so, and that GIPA faced resistance from program managers. Three respondents (13%) wrote in the "other" response category that PLHA groups are not always willing to work together and that current environments sometimes foster conflict and competition among the groups. Nine percent of respondents noted the general lack of funds for GIPA-related activities and challenges.

---

[9] See C.M. Roy and R. Cain. 2001. "The Involvement of People Living with HIV/AIDS in Community-based Organizations: Contributions and Constraints." *AIDS Care* 13(4): 421–432; Horizons Project. ND. *The Participation of PWHA in Community-Based Organizations.* Washington, DC: Population Council, Horizons Project. www.popcouncil.org/horizons/ressum. Accessed 4/2/03.

Figure 4. Perceived Barriers to GIPA within Organizations, for Selected Missions, IAs and NGOs in Five Asian Countries: 2003

Bar chart. Y-axis: Percent (0 to 80). Categories:
- Lack of needed skills: 74
- Lack of funds for volunteers: 35
- Health issues: 30
- Resistance from program managers: 26
- PWHA unwilling to participate: 26
- Issues between PWHA groups: 13
- Lack of funds for GIPA programs: 9
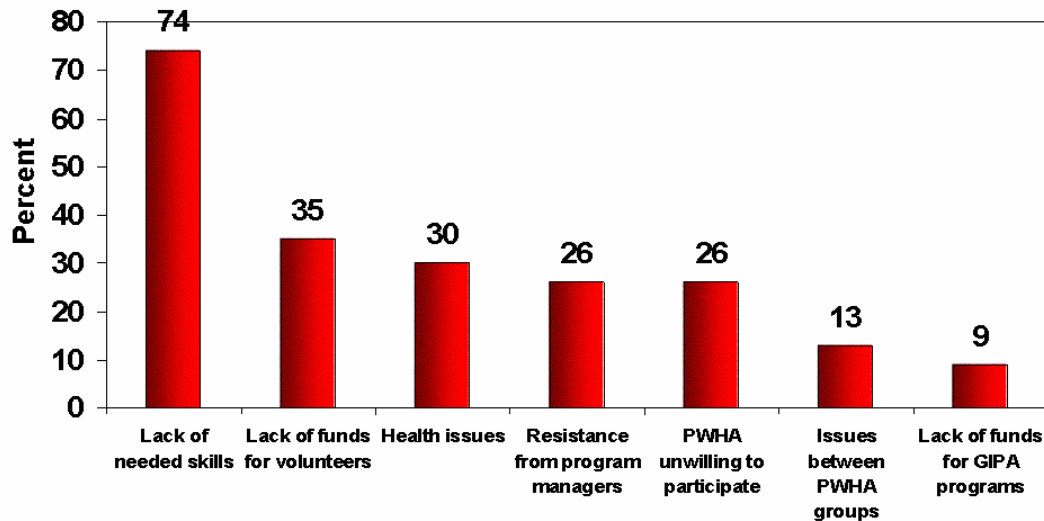
G.   Missions, IAs, and NGOs have used a variety of strategies to overcome challenges to GIPA

Respondents from 15 of the 23 Missions, IAs, and NGOs gave examples of successful strategies their organizations had used to address or overcome challenges related to GIPA within their organizations or in their programs or projects. Strategies have included improving skills, conducting advocacy and policy dialogue to generate support for GIPA, expanding networks of PLHA organizations and fostering collaboration among the groups, focusing on recruitment strategies, addressing poor health, and fostering GIPA in project decision making (Box 3).

Box 3. USAID, IA, and NGO Strategies for Overcoming Challenges to GIPA

Improving skills of PLHA
- Providing training to improve PLHAs' knowledge and skills; facilitate 'learning by doing'
- Linking PLHAs with capacity building and leadership training
- Working with support groups to help build skills in managing group activities
- Identifying talented members of PLHA networks and training them as second and third level leaders to take the place of leaders who become sick
- Building capacity of PLHAs to be research partners

Conducting advocacy and policy dialogue to generate support for GIPA
- Conducting a GIPA forum at the state level
- Using a workshop setting to sensitize program and policy managers to the needs of PLHAs and the benefits of involving PLHAs at all levels
- Conducting activities to reduce stigma and discrimination
- Addressing resistance through advocacy and gentle pressure
- Fostering advocacy by PLHAs to help create an enabling environment
- Working collaboratively with a range of government and NGO and international organizations to create a platform for GIPA-related activities
- Facilitating links between country and regional networks for PLHAs
- Working closely with relevant stakeholders in government and among nongovernmental and international organizations

Expanding PLHA networks and fostering collaboration among the groups
- Increasing PLHA networks to encourage people to come forward with group support
- Focusing on creating more safe space for people to 'come out' about their status
- Nurturing the new generation of PLHA leaders
- Holding collective, sometimes informal, meetings of all groups to learn the meaning of solidarity and to learn about relevant topics, such as nutrition, etc.
- Collaborating with NGOs that work with PLHAs to provide job opportunities and capacity building training

Focusing on recruitment strategies
- Recruiting people who are willing to participate in the program
- Providing incentives to encourage PLHAs to participate
- Attempting to ensure participation of at-risk individuals or groups in the absence of known PLHAs

Addressing poor health
- Supporting links to ART and other health services
- Referring PLHA volunteers for health care provided at subsidized or no cost to offset small honoraria they receive

Fostering GIPA in project decision making
- Including PLHAs in decision-making bodies of the projects

H.   Countries face barriers to GIPA

When asked about the main barriers preventing GIPA in HIV/AIDS planning, programs, and policy-making processes of the countries in the assessment, fear of disclosure/stigma and discrimination was by far the most noted barrier, mentioned by 87 percent of the respondents from USAID, IAs, and NGOs (Figure 5).   Seventy-four percent of respondents noted that lack of skills among PLHAs to meaningfully participate was a barrier, although respondents were not asked to list the types of skills needed.   The third most common response, indicated by 43 percent of respondents, was that PLHAs lack the resources needed (e.g., transportation) to meaningfully participate.   Lack of treatment options and health issues and were mentioned by 35 percent and 30 percent of respondents, respectively.   Hostile laws or policies and resistance by policymakers, each noted by 13 percent of respondents, were not perceived as major barriers to GIPA.

Figure 5. Perceived Barriers to GIPA at the Country Level, for Selected Missions, IAs and NGOs in Five Asian Countries: 2003
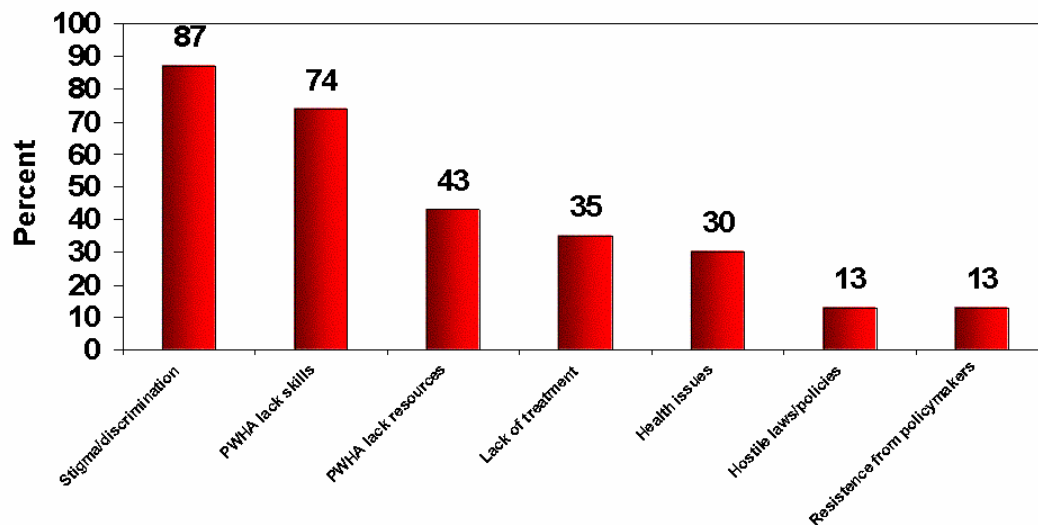
Respondents from all of the organizations had ideas for overcoming barriers to GIPA in the countries in which they work. These ideas, listed in Box 4, include reducing stigma and discrimination, increasing access to VCT, improving health care and access to treatment, strengthening capacity of PLHAs and PLHA organizations, increasing knowledge about HIV/AIDS and strengthening understanding of the need for GIPA, encouraging PLHAs to be spokespersons for HIV/AIDS, and reviewing and revising laws and policies related to HIV/AIDS and PLHAs.

Box 4. Suggestions to Overcoming Barriers to GIPA in the Five Asian Countries

Reduce stigma and discrimination in the community, workplace and health care settings
- Normalize the issue of HIV/AIDS in all walks of life—health, education, employment
- Develop advocacy and sensitization programs to address the attitudes of the community, religious and political leaders, and other key stakeholders
- Conduct anti-discrimination campaigns encouraging PLHAs to speak out
- Mobilize the community to provide care and support to PLHAs

Increase access to VCT
- Increase access to testing and counseling
- Incorporate information about opportunities for PLHAs to make a contribution to community and national prevention efforts and in the care of people living with HIV

Improve health care and access to treatment
- Introduce and increase access to ART
- Train PLHAs in self-care, recognition of symptoms of opportunistic infections, and preventive medication
- Refer PLHAs to user-friendly service providers in the health care sector
- Allocate additional funds for treatment and eliminate barriers to treatment, such as lack of transportation to service delivery sites, as well as the high cost of drugs
- Push treatment programs farther down the health system from the referral hospital level

Strengthen the capacity of PLHAs and PLHA organizations
- Provide more support to national positive people's networks by identifying and nurturing more leaders, particularly women, who can be effective advocates and be part of planning, programs, and activities
- Encourage networking to have a united voice among PLHAs
- Provide capacity building of PLHAs in program management and sustainability
- Assess PLHA capabilities, provide appropriate training, and place PLHAs in appropriate positions after training
- Use a human rights-based approach to involving PLHAs
- Provide income-generating skills, link PLHAs to various financial schemes, and establish vocational centers for PLHAs
- Strengthen PLHA support associations
- Ensure GIPA in decision-making processes related to programs directly affecting them

Increase knowledge about HIV/AIDS and strengthen understanding of the need for GIPA
- Increase understanding about transmission and nontransmission, promotion of compassion both among the PLHAs and communities
- Sensitize policymakers to GIPA, including understanding how they and their organizations can benefit from implementing it and showing successful stories of PLHA involvement; PLHAs at higher levels should be involved in these sensitization activities

Encourage PLHA to be spokespersons for HIV/AIDS
- Encourage PLHA volunteers to participate in education programs and social marketing campaigns to enhance HIV prevention

Review and revise laws and policies related to HIV/AIDS and PLHAs
- Ensure that PLHAs are not left vulnerable due to laws and policies
- Enforce existing laws and policies related to human rights and PLHAs
- Involve PLHAs in review and revision of unfriendly or tokenistic policies

I. *Training and awareness raising for managers and staff, capacity development for PLHAs, and direction from donors to ensure GIPA are needed to promote GIPA*

Respondents in USAID Missions, IAs, and NGOs were asked to identify activities that would help their organizations increase GIPA in planning, programs, and policymaking (Figure 6). The two most pressing needs identified were GIPA-related training for staff and management, mentioned by 74 percent of all respondents, and leadership and capacity building for PLHAs, noted by 70 percent of respondents. Close to half of the respondents (48%) also noted the need for greater awareness about GIPA among staff. One-third (35%) of the respondents noted that stronger policy guidance from donor organizations is needed to increase levels of GIPA within their organizations. The same percentage (35%) also mentioned the need for greater awareness about GIPA among managers to help promote GIPA. Twenty-six percent said that their organizations required additional funding for PLHA volunteers.

Figure 6. Perceived Needs for GIPA Within Organizations, for Selected Missions, IAs and NGOs in Five Asian Countries: 2003
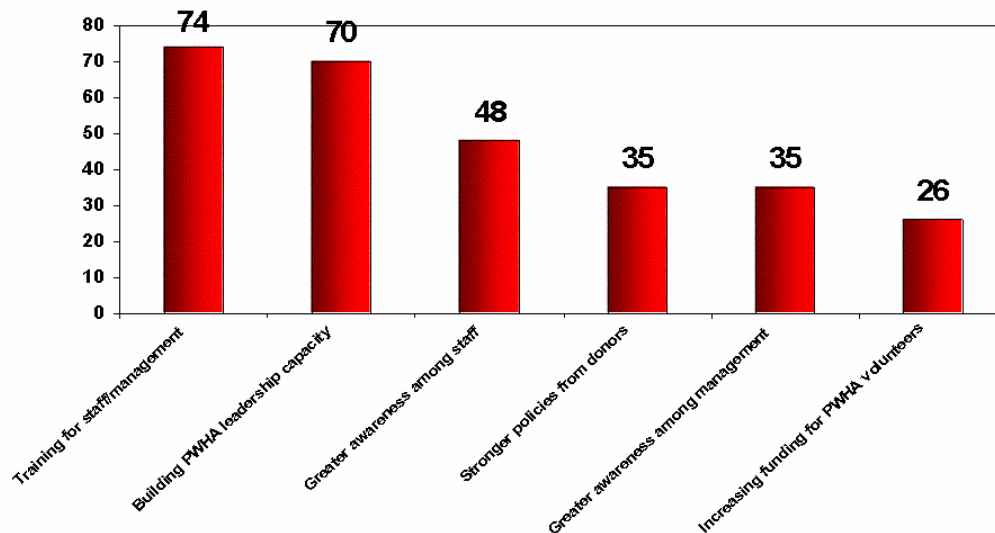
J.   Leadership and capacity development for PLHAs and greater awareness of GIPA is needed in each country to ensure meaningful involvement of PLHAs

Respondents were also asked what PLHA communities in the country need to increase their involvement into each organization's planning, programs, and policymaking activities. Within PLHA communities, priority needs, included leadership training for those in top positions in the PLHA organizations (many of whom will be leading organizations for the first time) and relevant capacity development for those who are carrying out activities in the PLHA organizations (87%), greater awareness of GIPA (78%), and a friendlier policy environment (30%) (Figure 7).   Box 5 lists some comments from respondents elaborating the needs among PLHA communities.

Figure 7. Perceived Needs for PWHA to Foster GIPA in Countries, for Selected Missions, IAs and NGOs in Five Asian Countries: 2003
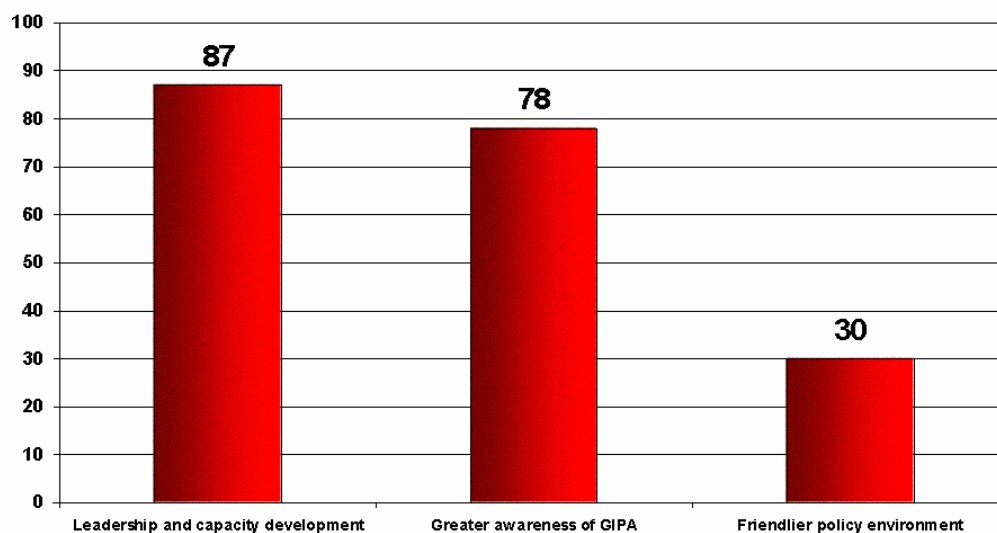
+---+
| |
| **Box 5. PLHA Community Needs to Foster GIPA** |
| |
| ● The GIPA document needs to be converted into an operational |
| manual, rather than a set of doctrines. Methods of |
| operationalization need to be incorporated into it. |
| |
| ● Every donor has promotion of the GIPA principle in its agenda, |
| but there is no coordinated effort among donors to promote it. |
| Therefore, the results in the country have not been very |
| effective in relation to the resources invested in it. |
| |
| ● Monitoring and evaluation are needed to ensure that activities |
| are on target, effective, and funded. This will also |
| demonstrate the impact of GIPA. |
| |
| ● Without political will, GIPA can never become reality. But, |
| unless leaders and politicians understand the rationale behind |
| GIPA, there would never be political will…Unless and until the |
| general population see the human face of the AIDS pandemic and |
| empathize with PLHAs, they will never agree with PLHA |
| involvement. |
| |
| ● In [one part of the country alone], there are seven different |
| small groups of PLHAs… However, there is a clear lack of |
| capacity within these groups. It is essential that the groups |
| collaborate and also be strengthened in order for the GIPA |
| principles to be followed. |
| |
+---+

K.   Respondents from USAID, IAs, and NGOs see benefits of GIPA to their organizations

Ninety-one percent of respondents from the three types of organizations believe that their organizations' planning, programs, and policymaking activities would be enhanced by GIPA.   One respondent voiced the opinion of a number of others by saying that *"GIPA helps to ensure that the program activities are responsive to the needs of those intended,"* just as any program should include the intended beneficiaries in planning and implementing activities.   Another added that *"PLHAs have a legitimate role/powerful voice to influence policy formulation given the idea that the developed policy will be directly affecting or helping them."*   One respondent added that, *"In monitoring and evaluation of care and support services for PLHAs, the best critical suggestions can be expected from PLHAs."*

Other respondents noted that GIPA gives an active voice to PLHAs, that it leads to empowerment, increased self-esteem, and a better quality of life for PLHAs and that it can help reduce stigma and discrimination.   Having PLHAs active in all levels of program activities can help *"motivate others to participate in the program"* and *"greatly enhances the acceptance and involvement of the target group."*

16

L.   Respondents from USAID, IAs, and NGOs see benefits of GIPA to the countries

When asked how GIPA contributes or could contribute the HIV/AIDS planning, programs, and policymaking processes in the country, one respondent said that GIPA could make a difference in all aspects of HIV/AIDS work. *"GIPA could contribute to the respect of PLHA rights, improvement of effectiveness and relevance of programs, reduce fears of discrimination, and improve the livelihood situation of some HIV/AIDS-affected households."* Another respondent noted that PLHAs *"contribute by adding a voice of the community to an overly medicalized and bureaucratic process. These people tend to be marginalized and at highest risks, exactly the kind of voices that we rarely hear in Ministry of Health meetings."* Another respondent noted that GIPA can change the mindset of all people involved in HIV/AIDS work—to putting more value on PLHA opinions and contributions. PLHAs should be part of policymaking, although one respondent noted that involvement has to be meaningful to be effective. Having unqualified PLHAs at the table or having PLHAs at the table but without voting rights, for example, are not effective. One respondent noted the need for donor mandates *"that PLHAs have a role in HIV/AIDS donor planning meetings, in health sector reform discussions, and external review of [government HIV/AIDS] strategies."* Another said that PLHAs should be *"part of a multisectoral national body mandated by law."*

M.   Some respondents see drawbacks to GIPA

Among respondents from USAID, IAs, and NGOs, 27 percent considered that there are some drawbacks to GIPA in their organizations. When asked to describe the potential drawbacks of GIPA for organizations and the country more broadly, one respondent noted that *"increased involvement per se does not have drawbacks. But, if strict screening procedures and training schedules do not precede it, PLHAs who are not appropriately qualified or capable may become involved, leading to a reduction in quality."* Another respondent made a similar point saying that all PLHAs do not necessarily have the capacity to participate in policymaking.

Some respondents noted that the focus on GIPA is overshadowing the need to provide basic needs, including employment, for PLHAs and the need to maintain *"an effective prevention-to-care continuum"* in programs. One respondent noted that *"They are mostly focused on international concerns such as stigma and discrimination without first responding to the basic needs and concerns of their members."* Another respondent said, *"Due to lack of availability of appropriate treatment for PLHAs, there might be times that ill-health of the individual might affect the quality and efficiency of their work as well as affect services of the organization."* One respondent said that GIPA should be linked with access to treatment and care. *"If GIPA is truly embraced then so should be making ART and linked health services available to PLHA leaders, managers, staff, and volunteers."*

Other respondents worried about the *"possibility of co-option and therefore tokenistic and meaningless programs and policies that do little to advance PLHAs,"* and that *"the concept of GIPA if superficially implemented leads to wasting of resource and frustrating*

the organization involve, including decision makers/policy makers." One respondent indicated that GIPA is hampered because stakeholders do not have a clear understanding of its value. Finally, a respondent noted that GIPA is a long-term prospect but that projects have short timeframes, which can hamper its implementation.

N. **Promoting GIPA has resulted in a range of achievements related to institutionalizing GIPA and GIPA outcomes**

Despite some perceived drawbacks to GIPA, IAs and NGOs noted a number of internal and external achievements related to their GIPA activities (Figure 8). Nearly half (47%) of the IA and NGO respondents noted that their organizations have included statements on the importance of GIPA in organizational plans. Over one-third (37% each) noted an increase in PLHA participation in local, national, or international conferences and meetings; an increase in PLHA participation in program planning and design; and in development of policies guiding programs. Thirty-two percent each indicated that there has been an increase in PLHA groups and in PLHAs in management positions in the IAs and NGOs. One-quarter (26% each) indicated that GIPA has resulted in inclusion of statements regarding the importance of GIPA in national plans and policies and an increase in disclosure of status among PLHAs in the country. Twenty-one percent each said that PLHAs were more involved in national planning and in decision-making bodies.

Figure 8. CA and NGO-perceived GIPA Achievements, for Selected IAs and NGOs in Five Asian Countries: 2003
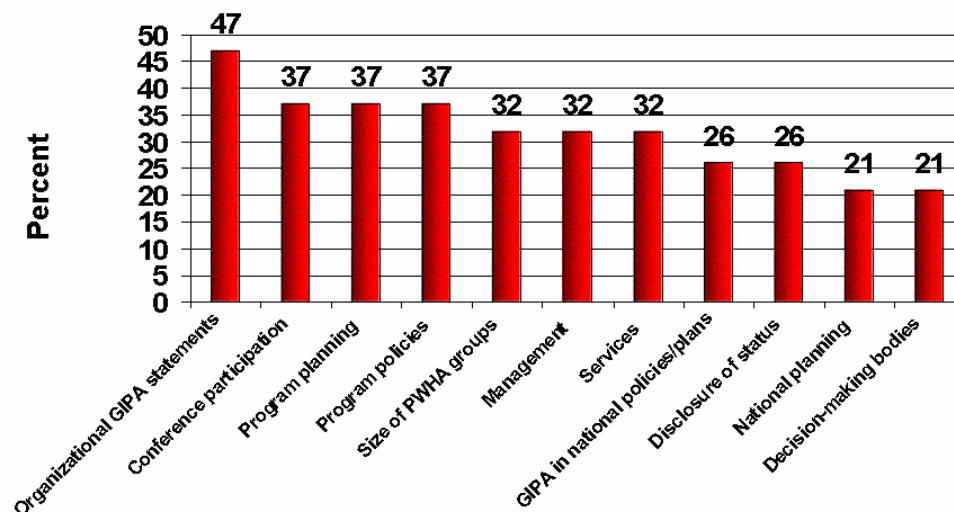
Note: The responses indicate that there is greater involvement of PLWHA in these activities or that GIPA is reflected in the activity, e.g., increased number of organizational statements in support of GIPA.

18

IV.   Issues and Recommendations

A number of issues regarding GIPA emerged from this assessment. Recommendations to address each of these issues are provided to assist USAID, IAs, NGOs, and other stakeholders to foster GIPA by enhancing efforts to involve PLHAs at all levels in the response to HIV/AIDS. The issues and recommendations relate to the organizations themselves as well as to the projects they implement.

▣ *USAID, IAs, and NGOs*

Not all organizations see the applicability of GIPA to their work.

> **Recommendation**
> USAID should encourage its Missions and the organizations it funds to examine the relevance of GIPA in their in-country work and to develop means for applying it. Within organizations, managers and staff would benefit from awareness raising on GIPA. USAID should give organizations that implement its programs clear mandates to incorporate GIPA in HIV/AIDS activities.

GIPA principles are not translated into clear guidelines on implementation.

> **Recommendation**
> USAID, other donors, and organizations that implement HIV/AIDS activities should work together to develop operational guidelines on how to implement GIPA principles at both the organizational and project activity levels. The guidelines should be widely disseminated in the ANE region and beyond.

USAID Missions do not have any direct means to involve PLHAs in their strategic planning processes.

> **Recommendation**
> Missions should identify and establish means for ensuring GIPA in their own internal work. GIPA within USAID Missions could include hiring openly HIV-positive staff, creating a planning or advisory committee to assist Mission staff to identify programmatic priorities, review strategic plans, or evaluate program activities.

Training of managers and staff of USAID Missions, IAs, and NGOs is needed to facilitate increased application of GIPA into organizational and program activities.

> **Recommendation**
> USAID Missions in the ANE region should facilitate the development and implementation of a comprehensive training program on GIPA for Mission, IA, and NGO managers and staff. The training curriculum could be based on and complement the guidance document recommended above, with PLHAs playing key roles serving as trainers and facilitators.

GIPA is occurring mainly at lower levels of the UNAIDS involvement continuum.

> **Recommendation**
> USAID Missions and the organizations they fund should be encouraged to foster trained and qualified PLHA involvement at all levels of the organization and in project activities. Technical assistance to assist in this effort, as needed, should be funded by USAID.

▣ *PLHAs*

Stigma and discrimination continue to be significant barriers to GIPA.

> **Recommendation**
> Missions, USAID/Washington, and IAs should continue to develop and implement innovative methods to reduce stigma and discrimination. Having trained and qualified PLHAs in leadership positions within the various types of organizations could send a powerful message and be an important strategy for stigma reduction.

Stigma and discrimination, particularly among target groups such as IDUs and prostitutes, and low economic status of many PLHAs, including women, result in underrepresentation of these groups in PLHA organizations.

> **Recommendation**
> USAID should support the development of special initiatives to ensure that leaders and representatives of PLHA communities reflect and represent affected populations relative to the epidemiology of the epidemic. Positive women, who also suffer from gender-related inequities throughout the region, should be particularly supported to participate in PLHA groups, including in leadership positions.

Training and capacity-building activities with PLHAs should be developed based on systematic processes for identifying opportunities for PLHA involvement and needs assessments of PLHA skills, abilities, and interests.

> **Recommendation**
> USAID should support a systematic assessment of capacity-building needs of PLHAs; development of a comprehensive multilevel training curriculum; and an ongoing, country-specific, and regional inventory of opportunities for PLHA involvement. PLHA networks could play a prominent role in carrying out these activities.

Sustaining GIPA is hampered by poor health, lack of treatment, and other factors related to lack of resources.

Recommendation

Missions, USAID/Washington, and IAs should identify and implement appropriate policies and means to provide increased access to treatments, including ART, and other financial and nonfinancial incentives to encourage GIPA.

Lack of income to meet basic needs and cover necessary costs associated with participation are a barrier to sustained PLHA involvement.

Recommendation

USAID should consider a policy allowing for the use of project funds to cover necessary PLHA costs associated with their involvement in HIV/AIDS project activities. USAID should consider adopting the Department of Health and Human Services' guidelines for reimbursement: "Reasonable and out-of-pocket expenses include transportation, meals, babysitting fees, and lost wages."[10]

Local politics, conflict, and competition among PLHA groups can have a negative impact on efforts toward GIPA.

Recommendation

Factors that may lead to conflict and competition among PLHA groups should be further explored. Policies and strategies for addressing potential or actual conflict among PLHA groups should be developed and incorporated in all GIPA-focused activities funded by USAID.

▣ *Policymakers, Program Managers, and Civil Society*

Policymakers, program managers, and civil society do not always see the value of GIPA.

Recommendation

Organizations that implement HIV/AIDS projects and activities should include activities to sensitize government leaders and program managers, in addition to civil society leaders and the general population on the needs of PLHAs and the value of including them in policy development, and programs to prevent the spread of HIV/AIDS and mitigate its impact. The commitment of policymakers and program managers, in addition to donors and implementing organizations, is crucial to the effective implementation of GIPA.

---

[10] Department of Health and Human Services (HHS). 2000. Guidelines for Reimbursement of Individuals Serving on a Ryan White Title I Planning Council and/or Title II Consortium. Formerly a Program Guidelines Memorandum. Issued in January of 1997 and 2000. Washington, D.C.: HHS.

V. Conclusion

Many of the findings contained in this report are not unique to the ANE region. In fact, the issues and concerns voiced by respondents in this study echo those by PLHAs in many national and international forums and confirm findings contained in other GIPA research.[11]

The "State of GIPA" in ANE, and in other parts of the world, can be best summarized by the observation contained in the UN's 2002 report on progress toward implementation of the Declaration of Commitment on HIV/AIDS:

> Organizations and networks of people living with HIV/AIDS are increasingly visible and influential at the global level and in many countries, but remain the world's most underutilized resource in the response.[12]

Undeniably, much progress has been made in advancing GIPA goals in the ANE region. The many GIPA-related activities supported by Missions and described by respondents in this assessment, along with other efforts by the UNDP, the International Health Alliance, and other international and local organizations are a testament to the progress made. The formation of the regional *Asia Pacific Network of People Living with HIV/AIDS,* funded in part by one of the IAs in this assessment, and the 23 subnational PLHA organizations in ANE listed in the USAID Directory of Associations of People Living with HIV/AIDS is tangible evidence of efforts bearing fruit.

However, visibility and participation of PLHAs is not even across individual countries in the region, although by 2003, PLHA groups had formed or are forming in each of the five countries. Moreover, many of the PLHA organizations in ANE lack the needed infrastructure and financial resources to accomplish their goals. Likewise, while commitment of the few involved PLHAs is abundant, there is a significant need for capacity building, leadership development, and training in a wide range of issues to translate commitment and visibility into meaningful involvement. Or, as stated by UNAIDS, "GIPA activities cannot count indefinitely on individuals' motivation or charisma…it is of utmost importance to provide training and support to PLHAs actively involved in the response to the epidemic".[13] There is also a critical need for support for treatment and other health care if leaders are to continue in their roles with the organizations and have time to groom new generations of leaders.

---

[11] See C.M. Roy and R. Cain. 2001. "The Involvement of People Living with HIV/AIDS in Community-based Organizations: Contributions and Constraints." *AIDS Care* 13(4): 421–432; Horizons. ND. *The Participation of PLHA in Community-Based Organizations.* Washington, DC: Population Council, Horizons Project. www.popcouncil.org/horizons/ressum. Accessed 4/2/03.

[12] United Nations. 2002. *Report of the Secretary General on Progress Toward Implementation of the Declaration of Commitment on HIV/AIDS.* New York: United Nations.

[13] UNAIDS. 1999. "From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)." *UNAIDS Best Practice Collection.* Geneva: UNAIDS.

Local politics, conflict, competition among and within PLHA groups, and lack of accountability of PLHA organizations to their communities—a dynamic but little discussed issue in GIPA studies to date—may also pose a barrier to increased involvement. This merits a closer look.[14] Is the perceived availability of funds for PLHA networks and potential income opportunities for its members contributing to competition among various groups or various individuals? Is conflict related to differing characteristics of members that make up the majority of the group? For example, is conflict emerging between "MSM groups" and "women's groups"? Or is conflict more a reflection of individual personalities, particularly those of the groups' leaders? Do donor organizations and implementing partners stymie grooming of additional PLHA leaders, including women, by continually supporting the same PLHAs for activities, including international travel to conferences?

Viewing PLHA involvement in ANE through the UNAIDS' GIPA pyramid of involvement (see Appendix), indicates that the GIPA activities undertaken by USAID, IAs, and NGOs have resulted mainly in involvement at the lower levels of the pyramid. The dynamic of having relatively high levels of PLHA involvement, but with little decision-making or policymaking power, is a common situation in many countries. Ideally, GIPA should mean having PLHAs in a variety of positions at different levels.[15] Otherwise, programs run the risk of promoting tokenistic participation among PLHAs. Programs may be unable to maintain interest and sustain involvement among PLHAs and may foster skepticism among this group about how meaningful their participation really is.[16]

As more PLHAs gain experience and hone their skills and leadership styles in HIV/AIDS organizations and work on project activities, a primary challenge for USAID and its implementing partners will be to identify and put in place concerted and specific actions to assist PLHAs in reaching higher and more meaningful levels of involvement. This assessment has identified a number of steps undertaken by organizations—and a number of recommendations for further actions—in the five counties to involve PLHAs. Strengthening ongoing efforts and supporting and replicating similar efforts will help PLHA communities in these and other Asian countries to progress toward a fuller realization of GIPA goals.

---

[14] This issue is reminiscent of a dynamic that surfaced in the United States among local PLHA networks and other AIDS service organizations representing different populations as more funds became available in the late 1980s and early 1990s.

[15] UNAIDS, 1999. "From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)." *UNAIDS Best Practice Collection.* Geneva: UNAIDS.

[16] C.M. Roy and R. Cain. 2001. "The Involvement of People Living with HIV/AIDS in Community-based Organizations: Contributions and Constraints." *AIDS Care* 13(4): 421–432.

Appendix: Pyramid of Involvement by PLHAs

Figure 1. A pyramid of involvement by PWHAS

This pyramid models the increasing levels of involvement advocated by GIPA, with the highest level representing complete application of the GIPA principle. Ideally, GIPA is applied at all levels of organization.

Level of involvement

DECISION MAKERS: PWHAs participate in decision-making or policy-making bodies, and their inputs are valued equally with all the other members of these bodies.

EXPERTS: PWHAs are recognized as important sources of information, knowledge and skills who participate – on the same level as professionals – in design, adaptation and evaluation of interventions.

IMPLEMENTERS: PWHAs carry out real but instrumental roles in interventions, e.g. as carers, peer educators or outreach workers. However, PWHAs do not design the intervention or have little say in how it is run.

SPEAKERS: PWHAs are used as spokespersons in campaigns to change behaviours, or are brought into conferences or meetings to "share their views" but otherwise do not participate. (This is often perceived as "token" participation, where the organizers are conscious of the need to be seen as involving PWHAs, but do not give them any real power or responsibility.)

CONTRIBUTORS: activities involve PWHAs only marginally, generally when the PWHA is already well-known. For example, using an HIV-positive pop star on a poster, or having relatives of someone who has recently died of AIDS speak about that person at public occasions.

TARGET AUDIENCES: activities are aimed at or conducted for PWHAs, or address them en masse rather than as individuals. However, PWHAs should be recognized as more than (a) anonymous images on leaflets, posters, or in information, education and communication (IEC) campaigns, (b) people who only receive services, or (c) as "patients" at this level. They can provide important feedback which in turn can influence or inform the sources of the information.
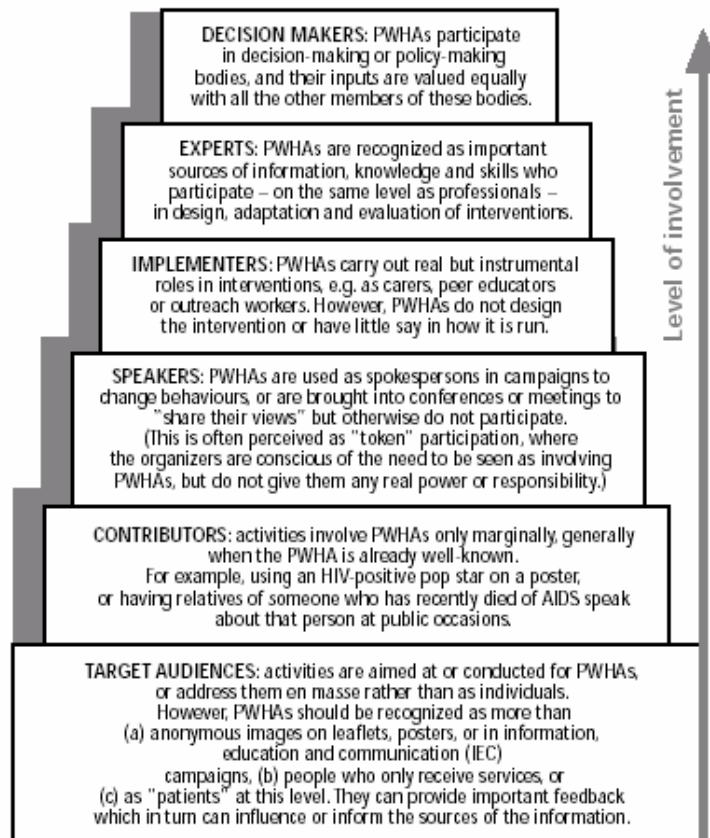
Source: UNAIDS. 1999. "From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)." *UNAIDS Best Practice Collection.* Geneva: UNAIDS.